

## PDBP Recruitment Continues

As of April 27, 2015, a total of 1264 participants has been enrolled in the PDBP and this represents 89% of the total anticipated enrollment for the Program. Thanks to these participants there is a substantial collection of biospecimens being housed at the NINDS biorepository: over 260 CSF samples and collectively more than 3800 RNA, DNA, plasma and serum samples. As the Program nears the end of its third year, steps are being taken to promote the use of these samples in hopes of accelerating biomarkers research. Although recruitment is going well, there is still a great need for participation from healthy controls. ■

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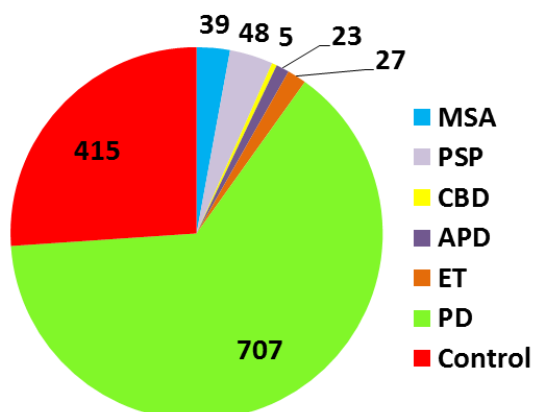
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Number of PDBP participants based on diagnosis



*Maria Elena Bolanos (left), who suffers from MSA, is taking part in PDBP at the University of Florida site. Her sister, Millie (right), is also participating as a control.*

### Patients' Corner

#### The Bolanos Sisters

*By Amy Snyder*

Millie, an employee at the University of Florida, has always been on the search for opportunities to participate in research. After her sister's MSA (Multiple System Atrophy) diagnosis in 2012, they both enrolled in Dr. David Vaillancourt's PDBP study; Maria Elena as a patient, and Millie as a control. When asked about their dedication to research, both Millie and Maria Elena expressed deep roots in their mother's desire to be a physician. Millie narrates their mother's story about how in addition to her career aspirations she had always wanted to raise a family but "back in those days it was very hard for a woman to do both, let alone be accepted into the medical profession."

Immediately after Maria Elena's diagnosis, both sisters began their quest for

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information. It is the philosophy of the Bolanos family that you are your own best advocate when it comes to healthcare. Maria Elena has been instrumental in finding doctors she feels connected to and is confident that taking this active role has led to the best care possible.

Upon meeting Maria Elena, it is clear that she is incredibly strong and independent. Despite her diagnosis, she still finds joy in doing things for herself and wants to maintain her independence as long as possible. From talking to both sisters it is clear that these are difficult waters to navigate, especially as new symptoms arise. When speaking about words of wisdom for others in their situation, the Bolanos sisters expressed the importance of fostering open and honest communication, as well as patience for the process.

From the very beginning, our lab has felt privileged to work with a family that has such dedication and passion for science. This is especially evident in Millie's expression of the pride and gratification that come from participating in research studies. Maria Elena's philosophy aligns with her sisters and her advice to other patients in the study is simply to "stay positive, don't give up, and educate yourself." ■

***Amy Snyder is a clinical coordinator working with Dr. David Vaillancourt at the University of Florida.***




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***"Everyone is telling me 'sit down, don't do this, don't do that'....but I do it anyway!" - Maria Elena Bolanos***

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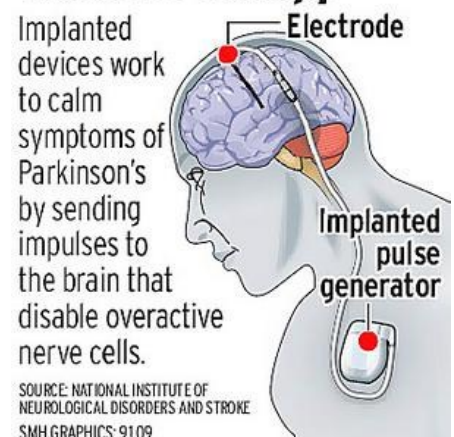
## What is DBS?

**Deep brain stimulation (DBS)** involves surgically implanting electrodes into a specific part of the brain to deliver electrical currents. This procedure is used to alleviate symptoms from Parkinson's disease patients who are not sufficiently responsive to medications.

How do researchers and clinicians know where in the brain should the electrode be placed? Current practice relies on research of the brain circuitry responsible for controlling motor movement. Part of this circuitry is a brain structure called the subthalamic nucleus, which is usually targeted in DBS partly because of its integral role in controlling motor movement. Another brain region that is targeted is the globus pallidus. Determining which of these regions to target for DBS usually depends on the symptoms and needs of the patient.

For more information, please see: [http://www.ninds.nih.gov/disorders/deep\\_brain\\_stimulation/detail\\_deep\\_brain\\_stimulation.htm](http://www.ninds.nih.gov/disorders/deep_brain_stimulation/detail_deep_brain_stimulation.htm)

### Wired for therapy



***Spotlight on PDBP Projects***

## Update on Parkinson's Research at UAB

*by Ashlee Brooke Rawlins*

For years, Andrew West has been studying a protein called LRRK2 (pronounced “lark two”) at the University of Alabama at Birmingham (UAB). His research shows that this enzyme plays a key role in the neurodegeneration occurring in Parkinson's disease. He believes that LRRK2-blocking drugs could be the first disease-modifying treatment available for Parkinson's that might slow or halt the disease in its tracks.



**Dr. Andrew West**

As part of the Parkinson's Disease Biomarkers Program, Dr. West and his team is using urine and serum samples obtained from the Movement Disorder Clinic at UAB to measure the concentration and activity of the LRRK2 protein in people with Parkinson's Disease and without the disease. Through this work, the team has identified that people who carry a LRRK2 mutation and have Parkinson's disease have very high levels of active LRRK2. This is an important discovery because this work provides a means to determine the effectiveness of future drugs that return LRRK2 levels back to normal in these individuals, to help ensure that an otherwise promising drug does not fail in the clinic because it was not used correctly in particular individuals. In addition, the team recently found that even in people who have Parkinson's disease and do not have a LRRK2 mutation, the LRRK2 protein appears to be moderately overactive so that future LRRK2-based drugs may give benefit to many more Parkinson's disease patients than originally thought. It is hoped that this work with LRRK2 biomarkers will help pave the way for drugs that can end Parkinson's disease. ■

*Ashlee Brooke Rawlins is the Project Manager working with Dr. West at the University of Alabama at Birmingham*

## Parkinson's Disease-Related Events

### Parkinson's Unity Walk, Saturday April 25, 2015

This year, as in previous years, thousands participated in a gentle 1.4 mile walk in New York's Central Park to raise awareness and funds for PD research. NINDS and numerous representatives from nonprofit organizations were available to share information and resources with members of the Parkinson's community. For more information see: <http://www.unitywalk.org>



*Drs. Beth-Anne Sieber (left) and Birgit Neuhuber (right) representing NINDS at the Parkinson's Unity Walk.*

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